

## **FASD - Fantastic Aaron Succeeds Despite.....**

As a mother of teenager with foetal alcohol syndrome I have come through quite an eventful journey and feel it is now time to speak up and be heard to make things better for many other families out there who have to live and breathe with this disability every day. Why am I doing it now? A little while ago Aaron woke up one morning and said 'I wish I was born with an ordinary brain'. It was heartbreaking for him to say that and I struggled to be able to reply to his statement.

I am the biggest advocate for my son but at times feel that my batteries run on empty. He is a very loving and caring person who wants to be liked. Often he will give me a cuddle and tell me 'he loves me' and other times he is oppositional, defiant and aggressive. The less structure in an environment the more likely he will struggle to self regulate his behaviour. The more complex the task or the rules the more likely he is to become disorganised and get 'stuck' with his thoughts. I have become an expert on how to manage and understand him and avidly read all the fantastic information coming from Canada. Through years of trial and error we feel we have now got a good circle of support around us who understand Aaron. He is also in a school that are prepared to do their best to meet his specific needs.

One of the biggest supports for our family is the Rainbow Afterschool Umbrella Club, based in Napier which caters specifically for children with special needs. My son has a valued role there and is always happy to go. Through the tough times when Aaron has not been at school they have stepped up and been our life line especially for us to be able work. There is concern over future funding and my plea to the Government would be to see this establishment as essential and working in supporting children with FASD as well as other disabilities.

Here in Hawkes Bay we are lucky to have the only Developmental Assessment Programme in New Zealand where the staff have the skills to complete a comprehensive neuropsychological assessment and diagnosis of Foetal Alcohol Spectrum Disorder. From this learning and behaviour strategies are recommended. It certainly made it much clearer for us, as to what level Aaron is functioning at and what his abilities and difficulties were. "Errorless learning" was a phrase I picked up and subsequently as we go through his teenage years I ensure he is around positive role models who know and understand his disability. I never leave things to chance as he needs to know the right way to behave from those around him. He is hardly left unsupervised for any length of time as he needs others around him to help him make the right decisions.

There are times that I wish it would all go away and that we had an ordinary kid who did not lose control and would learn from his mistakes. The biggest thing of all is making and keeping friends. My son rarely gets asked to birthday parties or sleepovers. This is

heartbreaking for Aaron and for us as parents. Again Rainbow Afterschool Umbrella has been a great resource for us with regard to Aaron having some buddies. They are care workers who are in their 20's and are awesome in the way they relate to Aaron. This has helped Aaron fill that ache of having hardly any friends.

It is hard when you look at most of these children as they look completely normal which is far from the reality. It is an invisible disability as serious as a child in a wheelchair except the environment around them is not geared up to manage them like it is for the physically disabled where most places have access, dropped kerbs, specially adapted taxis and so on. Our children have to try and make sense and function in the world around them with very little done to help support what I call 'The Wonky Brain'. They are put into mainstream schools where they flounder, become overwhelmed and then express this through deterioration in behaviour which can be very challenging and frightening for the staff if they have to witness a major meltdown.

With my own son he has been in a number of different schools and initially things would go okay as the funding and the resources were put in for him to settle in. Then the education system said 'he is doing fine now so we will take it all away'. No surprises as to what happens. Three times it has fallen down for my son and I'm sure I am not alone with this situation. It is not a happy place to be sitting in the Principal's office with the Board of Trustees making a decision to expel your child from school. You feel totally helpless, isolated and frightened for the future of your child. It is hard to fight the wheel of the education system. No one would take a wheelchair away from someone with quadriplegia so why take the supports away from our children.

These children have irreversible and lifelong brain damage which has been caused by pre-natal alcohol exposure. We have gone down the long road of applying for the ORRS funding which would ensure the school gets enough funding to put the resources to support and supervise your child. We failed and again schools will not really want your child with such complex needs if there is no money accompanying them. They can't cope and have to keep in mind the safety and learning for the other students in the class. Again I don't blame the education system as they again work within the budget constraints dictated by the Ministry of Education. We need to put FASD on the radar so that we get a bigger share of the cake. Schools need to have the appropriate and skilled support to manage these children. It is about thinking differently and using strategies that have been successful in Canada and the USA for years.

Many families are scared to come out of the closet and talk about their child's disability as people are too quick to blame the parents and think ill of them. As a result our country is still 'burying its head in the sand' as to the extent of the problem. Why is the rate of behavioural problems in schools becoming more prevalent? They are likely to be children with undiagnosed Foetal Alcohol Spectrum Disorder. These children are served with a life sentence which is preventable. How many women have a drink during pregnancy?

Pregnancy by accident increases the chance that alcohol will have been consumed. We live in a pro-alcohol society. Recent research shows that pregnant woman in New Zealand are consuming four times as much alcohol as the United States. This alcohol driven culture makes this a problem of our society and greater recognition and action is critical for the sake of this very vulnerable group of children who will grow up in an unforgiving society.

Blaming is a useless activity and will not help my child or others to succeed. With my own situation we adopted Aaron and even now I do not blame his birth mother. She was not brought up in a stable, loving home and did not have the opportunities to try and break out of the environment she found herself born into.

I say to all parents out there who have children with FASD to speak out. Canada and America have now got comprehensive programmes that work well to support and educate the community on what interventions and strategies are needed. I suggest reading the submission document on 'The Green Paper for Vulnerable Children', produced by the Foetal Alcohol Network New Zealand. ([www.fan.org.nz](http://www.fan.org.nz))

Write your story down and get it in the media, give it to your MP or email it to the Government. Strength in numbers is what will make the wheels of change move quicker.

The Government take in a lot of revenue from alcohol sales. In the submission document it stated an approximate amount of \$800 million per year on liquor excise tax. Surely some of this money needs to be channelled into the funding necessary to provide FASD – related services. It will be money well spent and I would say long overdue.

Lisa Smith

Proud mother of my son Aaron